<http://www.diva-portal.org>

Postprint

This is the accepted version of a paper published in *Journal of Advanced Nursing*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Kneck, Å., Klang, B., Fagerberg, I. (2012)

Learning to live with diabetes: integrating an illness or objectifying a disease.

Journal of Advanced Nursing, 68(11): 2486-2495

<http://dx.doi.org/10.1111/j.1365-2648.2012.05947.x>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:esh:diva-2935>

ABSTRACT

Aim: This paper is a report of a study of illuminating the meaning of “learning to live with diabetes” three years after being diagnosed.

Background: A changed situation e.g. in relation to living with diabetes, raises a need to understand. How time for experience contributes to this learning process for people living with diabetes is not yet well understood. It would therefore seem valuable to ask people, who have had diabetes over a similar length of time, to narrate their experience in relation to daily life situations in order to better understand how learning is established.

Methods: A life world approach was used, with interviews being conducted with 13 people who had been diagnosed with diabetes three years earlier. Data was collected in 2007, and analyses were conducted using a phenomenological-hermeneutic method.

Findings: How a person experiences the physical body was found to be crucial in the learning process. If the body with its signals is understood it can be a tool for experiencing and understanding the world and oneself. Feeling insecure about one’s own needs, and not trusting or understanding bodily signs, made participants dependent on others to make decisions for them. **Conclusion:**

This study showed that duration of illness was not of importance for the understanding of living with diabetes. Living with diabetes three years after being diagnosed meant to experience both an overall balance in one’s existence and a daily struggle.

SUMMARY STATEMENT

What is already known about this topic

- *Living with a chronic illness such as diabetes means being challenged by changes, which raises a need to understand, a learning experience.
- *Diabetes distress, suffering and loss are well-recognised problems.
- *People living with diabetes are expected to be active and take responsibility for their illness, providing the majority of their own care.

What this paper adds

- *How the person experiences the body, as an object or a subject, was crucial for how decisions were made.
- * 'The glucose meter, information, routines and others' experiences both facilitated and inhibited the learning process.
- * Duration of illness was not of importance for the understanding of living with diabetes. Living with diabetes three years after being diagnosed meant to experience both an overall balance in one's existence and a daily struggle.

Implications for practice and/or policy

- *Health care staff should listen to how people talk about their body so as to increase the understanding of how they integrate diabetes into the lived body.
- *Health care staff should be aware that technical tools can be experienced as both facilitating and inhibiting the process of listening to one's body.

* Patient education in a group setting, with the goal of sharing experiences in a learning process, will be meaningful only if the person has the ability to interact with others.

Keywords: Diabetes, chronic illness, experiences, interviews, lived body, lived experience

Title: Learning to live with diabetes – integrating an illness or objectifying a disease

INTRODUCTION

Despite medical and technological advances, a minority of people living with diabetes achieve the set goals for diabetes care, such as experiencing good physical and mental well-being. The inability to achieve those goals increases the risk of developing severe medical complications as well as experiencing suffering and diabetes distress (Norris et al. 2002, Skovlund and Peyrot 2005, Peyrot et al. 2005, Snoek et al. 2011). The prevalence of diabetes is increasing world-wide and has become a major health and economic concern (ADA 2003). In Sweden, diabetes is one of the largest disease groups, with approximately four percent of the population exhibiting one of its manifestations (Thunander et al. 2008).

People living with diabetes are expected to be active and take responsibility for their illness, providing the majority of their own care (Funnell and Anderson 2003, Tang et al. 2010).

BACKGROUND

Living with a chronic illness such as diabetes means being challenged by changes in relation to daily life and one's body (Charmaz 1983). When our previous knowledge no longer fits a situation, previous structures can no longer

meet the situation and tension arises. Piaget (1929) describes cognitive structures and Merleau-Ponty (1945/2002) explains this as the body schema (schéma corporal), structures or embodied pre-conscious habits providing the strength to respond to a situation. A need to meet these situations in a new way requires transformation of structures (Merleau-Ponty 1945/2002), a learning experience, regarded as a change in human beings' understanding of themselves or their life world (Jarvis et al. 2003). Schultz and Luckmann (1973, p. 224) discuss the need to expand the "*stock of knowledge*" in order to be better prepared to deal with life. The life world, where experience is formed and situations are met, becomes essential for understanding more (Dahlberg et al. 2008).

Meleis (2010, p. 11) writes that a changed health status might create a process of transition defined as "*a passage from one fairly stable state to another fairly stable state and it is a process triggered by change*". A transition is understood as comprising distinguishable phases following a chronological trajectory. Bridges (1933/2009) describes transition with three phases: ending, losing, letting go - the neutral zone - the new beginning, illuminating a linear process. Transition following a chronological order has been described by e.g. Price (1993), Hernandez (1996), Vég (2006), as going through different phases when coming to terms with living with diabetes. The initial phase is characterized by insecurity, anger, helplessness and loss (Price 1993, Hernandez 1995). The person is described as being passive compliant to

the recommendations from the health care service (Thorne et al. 2003). In the experimental phase the person is more active in figuring out “*what works for me*” (Price 1993, p.40). Kralik et al. (2004) and Kneck et al. (2011) found that people learn about their responses to illness through daily life as a result of trial and error. In the integrating phase the illness has become a natural part of daily life. The person has developed appropriate routines which can be modified to new situations (Price 1993, Whittemore and Dixon 2008). Others have found living with chronic illness as a fluctuating transition process. This on-going, shifting process is described by e.g., Paterson (2001), Kralik (2002) and Aujoulat et al. (2008). Reflection or “space for thought” was also important for “coming to terms with a new identity”, including changed attitudes and habits in relation to living with chronic illness (Asbring 2001, p.p. 316-317). Turning points, such as significant life events, have also been found to contribute to a change within a person (King et al. 2003). Whittemore and Dixon (2008) also discuss personal experience of the number and intensity of barriers and of the available resources as influences on this process.

A time span is an essential property of a transition (Meleis et al. 2000). Despite that, little is known about how time for experience contributes to the transition process of living with chronic illness (Paterson et al. 2001, Paterson 2001).

Thus, more knowledge of the transition of living with diabetes is needed to understand how health care staff can facilitate the transition process

to help people with diabetes to be active and feel responsible for their health and care. We need to know more about how learning is established in a person's life world and how time spent living with diabetes contributes to this process.

THE STUDY

Aim

The aim of the study was to illuminate the meaning of "learning to live with diabetes" three years after being diagnosed.

Design

The study has been carried out within a life world approach, with the purpose of capturing and understanding the entirety of the phenomena of interest (Dahlberg et al. 2008). To explore the phenomena of interest, interviews were conducted at a hospital, at the place of work or in the home, according to participants' preferences, and lasted approximately 50-70 minutes. The interviews began with the open-ended question: "How do you experience living with diabetes?" The participants were also asked to narrate situations where they took their diabetes into account. Probing questions that clarified and explored their narratives were asked when necessary, e.g. "Could you tell me more about that?" The interviews were audio-taped and transcribed verbatim by the first author. Data was collected in 2007.

Participants and data collection

The participants were recruited from an endocrinological ward at a Swedish metropolitan university hospital. A selective sampling approach was used to achieve maximum variation. Thirteen participants (29 – 68 years old), both women (4) and men (9), with different social and working conditions (3 living alone, 10 living with partners, 11 working, 2 not working), and different medical treatment and patho-physical cause (5 with type I and 8 with type II diabetes) made up the group. There was a requirement that the interviews should be conducted in Swedish. The participants received both written and oral information about the study shortly after being diagnosed and again after three years. Participants in this study had all been offered a week long course in diabetes self-management in line with the Swedish national guidelines for diabetes care.

Ethical considerations

All ethical guidelines were followed (cf. Polit and Beck 2009) The study was approved by the regional research ethics committee (Dnr 03-589).

Data analysis

The transcribed interviews were analysed using a phenomenological-hermeneutic method, involving three phases; naïve understanding, structural analysis and comprehensive understanding. All phases involved a constant

dialectic movement between the whole and the parts of the text, between understanding and explanation, towards a new understanding. The method was inspired by the philosophy of Ricoeur (1976) and has been developed by Lindseth and Norberg (2004). In the naïve understanding the text was read to get a sense of each interview and of the material in its entirety. The structural analysis aimed to identify parts and patterns of meaningful consistency and to seek explanation of the text. The text was divided into units of meaning, which were condensed, abstracted and then related to each other, based on similarities and diversities, in sub-themes and themes.

Table I: The analytic steps in the structural analysis

The comprehensive understanding aimed to deepen the findings, provide a philosophical anchorage and generate a scientific discussion. In the comprehensive understanding the naïve understanding, the structural analysis, the authors' pre-understanding and literature, as well as the context of the study, were brought together into a new comprehensive understanding (Lindseth and Norberg 2004).

Validity and rigour

During the process of analysis and writing, the emerging themes and understanding were discussed and reflected upon in order to make us aware of our pre-understanding (Dahlberg et al. 2008). The themes, sub-themes and the

comprehensive understanding were discussed in seminars in order to achieve “organized scepticism” (Merton 1973). The enrolment of the participants for the study took several months and aimed at achieving maximal variation. The same participants had also been interviewed shortly after being diagnosed by the same interviewer (xxxx), which probably contributed to the richness of the narratives given by the participants at this time. The interviews were transcribed by the interviewer/first author, and were found to be valuable for the analysis process. Member check had been considered but rejected, whilst participants’ lived experiences were abstracted, interpreted and de-contextualized, in line with e.g Sandelowski (1993).

FINDINGS

The findings report the naïve understanding, two themes and five sub-themes resulting from the structural analysis and the comprehensive understanding.

Naïve understanding

The interviews revealed the importance of experience of both freedom and control when living with diabetes. Integrating diabetes into life makes life easier, but it is sometimes hard to find balance in life anyway. Participants both listened to bodily signals and ignored them. Even if one approach was dominant for a person according to their life situation it could change. Signs were both physical and emotional symptoms.

Structural analysis

Table 2; Themes and sub-themes

The sub-themes have not been given headings. They are described in the theme and illustrated by quotations.

Making decisions by using different sources of information

When participants in this study received signs and symptoms from the body they interpreted, trusted and understood the body was the basis for decision-making. The body and self gave the person the answer to “How do I feel?” but also a feeling of control and the security that “I am the one who knows best my state of health”. Listening to and using the body was a way of feeling good in general. Taking care of one’s diabetes then meant taking care of the entire self.

I feel like..I don’t know if my stomach’s more sensitive.. I’ve changed my diet as well...my stomach can’t stand too much fat... like cream in a stew..that makes my stomach feel really bad (n 3)

The glucose meter was regarded as a helpful tool for understanding the body’s reactions. It was necessary to measure the glucose level more frequently when deviations from ordinary situations occurred.

Freedom was experienced through measuring, thus increasing the chances of doing what one wanted to do. At the same time the glucose meter became an obstacle, making it harder to rely on body signs.

The more I measure, the more I try to compensate and correct and the more it varies.. it is as if you are run by the meter more than

by your own head, so I think it works better... I eat when I'm hungry and not otherwise...., not according to the meter (n 13)

With more experience and the ability to listen to the body, one's own interest for certain topics served as a guide to choosing when and what to read, and was experienced as enjoyable, whilst at the same time contributing towards living with diabetes. Listening to the body also meant trusting signs and symptoms that could not be explained rationally, e.g. experiencing symptoms of decreased glucose level shortly after a meal. At the same time bodily signals that did not feel relevant could also create mistrust of the body. It was then hard to let those signals influence one's actions. Participants also ignored signs when they felt that they could not be given priority.

It's so difficult to know how your body feels.. it can hurt all over and I do not.. not bother... perhaps I should if my body tells me... but it takes a lot to get me to the doctor and things like that.. but that's how I've always been, which is silly (n 5)

Feeling insecure about their needs, and not trusting or understanding the bodily signs, made participants dependent on others to make decisions for them.

So my levels were so low.. almost low enough to make him (the doctor) worried .. I had been eating as I was supposed to, but he said I'd have to eat more fatty foods..as I have done, even though that wasn't what we were told to do exactly.. you've got to trust the doctors, haven't you, and try to do what they tell you – if they get it wrong, you get it wrong, if they get it right, it will be right, won't it? (n1)

This also meant participants in this study having to depend on health care staff or others to help them decide which information they needed. It was seen as an advantage to have factual information.

At the same time, previous or more general information needed modification when changes occurred, and not being able to do this could lead to a feeling of insecurity. It became necessary to keep a grip of what one already knew or had been told, even if this felt contradictory.

So then you were supposed to eat... so many calories and proteins and fat, and so I did, I did follow that but...now I haven't been following the plate rule so now I don't know, now I have a sort of in-between plate which makes it more difficult to know exactly...

(n 1)

Objective signs such as lab results, sampling and glucose monitoring were important in understanding how one's own body worked.

Finding a balance was a matter of constantly asking oneself what was most important and what was feasible in any specific situation. Illness was prioritised, e.g. returning home to collect syringes even though it meant arriving late for a social event. Illness could also be relegated to the background when something else felt more important. One example was choosing a higher level of glucose than normal to eliminate the risk of low glucose symptoms, e.g. when drinking alcohol or driving, thus focusing more on safety. A way to achieve a balance was to be more moderate, allowing

oneself what seemed good but still keeping within limits to minimize the negative impact on one's health.

Maybe you just take two sweets even though you really want ten or so because they're really good, but I don't, I mean you don't take ten sweets cos' you know you're going to have to go and get your insulin jab (n 10)

Choosing an alternative that was better for one's health created a feeling of not only being good for the diabetes but also for one's entire self. Making choices meant constantly asking oneself what to prioritise, weighing advantages against disadvantages e.g. another injection to attain an optimal glucose level, as opposed to the pain and effort caused by the injection and glucose sampling.

I don't want to take more insulin, so I don't... or at least just a little (insulin), but things still have to taste good, of course (n 10)

On the one hand, participants felt grateful for the resources available e.g. concerning food, treatment, information and medical equipment. On the other hand, life was invaded by constant efforts to remember medication and insulin, and by coping with pain from injections, blood samples and side effects, and participants expressed a wish to get rid of all this. It was also hard to handle the fact that one had to deal with this for the rest of one's life.

Decision-making in relation to illness and one's health could be easily done, as a natural part of daily life, or as a recurring struggle: as a constant sacrifice, a contradiction between having to choose in a particular situation between what

one thought would benefit the body and/or the disease and what one actually wanted or thought was possible to carry out.

One really annoying problem, I applied for.. a license to drive a motorbike and I ...filled in all the paperwork ...and everything, then I had it all back with like a refusal note because I'd said in my health statement that I had diabetes (n 8)

A struggle was also experienced when obstacles prevented one from fulfilling dreams.

Routines were experienced as providing a structure that made daily life with diabetes easier. It was also a positive feeling to let go of routines during holidays or leisure time, to decide for oneself what things to do and when to do them. This meant putting diabetes to one side, pretending it did not exist, but also feeling that relaxing routines meant trying and discovering new things, e.g. different food, other types of exercise in order to feel healthier.

It's good when you're at work, like at work you have routines... and you eat at roughly the same time and take your pills, and at weekends when you're off all that gets thrown out of the window (n 8)

Diabetes was also experienced simply as routines integrated into weekday life.

Solving the life-puzzle – a delicate balance to create a desired life

Participants experienced an increased confidence from others in their ability to live with diabetes. It was a good feeling not to be treated separately, but also

frustrating when others forgot that one always had energy- and time-consuming extras to think about.

Well, my girl doesn't even think about me having diabetes, I run it so well so I don't think she thinks about it the way I do, which I suppose probably means a risk that she gets a bit nonchalant as far as I'm concerned, so you sometimes have to shout a bit to get some help (n 3)

Participants had experienced people whom they could trust and share thoughts with, in particular close family members and partners. Others with appropriate experience were chosen as a resource for better understanding of themselves and their illness. This was mainly people with experience of diabetes or other chronic illness and health care. Participants were willing to listen to others, but valued their information and took it into consideration only if it felt relevant. It had to be not only good for the disease but also for the participant, implying that it should also fulfil other needs.

My Gran had diabetes.. she was scared to eat anything at all...so I've been over to her place and looked at her cake recipes, 'cos she likes to bake... so we've found some alternative recipes with less sugar.. so she's tried some new stuff that we test together.. and we've had a good time doing that
(n 5)

Learning to live with diabetes also involved being vulnerable when not being able to take care of yourself, and then being dependent on others: for example,

feeling dizzy when walking in the forest and realising that you had not brought anything to eat. Participants found a balance between being independent and dependent. They had in many ways chosen to be independent from the health care service; they preferred to get on with their own life and were able to do so, even if they also sometimes experienced more dependency on health care than previously. When participants had an overall feeling of being in control, it was sufficient to know that health care was accessible. However, not having a close relationship with the health care system also meant that it became harder to get care when required.

My doctor was really stressed out.. just said this looks fine and your levels are great and thanks and goodbye ...I don't know what else I wanted, but perhaps a bit more detail.. and a bit of time for a question or two (n 13)

Medical treatment and blood glucose levels were the focus for health care staff, whilst participants also wanted to discuss how to handle life in general.

A fluctuation between separating and integrating diabetes into one's being was shown. When diabetes was integrated meant the person being changed. Then it was not obvious that participants could recognize situations to narrate. Illness was involved in the body and life and had formed a new way of being. Living with diabetes was then experienced overall as easy; diabetes was a part of the "new me".

That's the whole point, I mean..., when you're up late in the evening and how hungry can you get and there's the fridge and

well... sleeping and eating habits, like sleeping affects diabetes
and eating affects diabetes, like the whole thing. (n 9)

The ability to integrate diabetes and experience balance varied among participants. Demanding life events or a change in body condition could also make it harder to experience balance. Diabetes was possible to ignore when life events were more crucial, but ignoring medical treatment and self-care meant putting aside the well-being of the entire self.

There was a reciprocity between feelings of wanting diabetes to be separated from oneself “the old me” and being a part of the person “the new me”.

Allowing oneself to be different meant experiencing both the disadvantages and advantages of a different life and self. Reflection on oneself and one’s life came with changed conditions for living.

So how bad is it having high sugar level anyway? I don’t notice any difference... like I don’t really know how long a long time is, do I?...who decides that anyway, is it like with radiation from mobile phones, they say it can get you a brain tumour but...but how long do I have to speak on the phone to get a brain tumour?
(n 8)

An awareness of changes in the illness, life and oneself also meant living with the uncertainty of not knowing what the future with diabetes might involve. Changes were now carried out or thought of in order to create a desired life, where diabetes is one part that influences and is influenced by the changes made. Participants talked about “daring to do what I have thought about for years”, allowing their own interests to be in focus.

I read an advert about.. proper shoes... and I thought I might as well try them, and since then I've had them all the time and now I couldn't do without them, they're really nice (n11)

After three years lifestyle changes had either become habits in daily life, or had been rejected.

Comprehensive understanding and reflection

The meaning of “learning to live with diabetes”, after three years’ experience, is understood as a fluctuation between balance and struggle. Being in balance means diabetes is integrated into the person’s entire existence forming a new way of being. This means that diabetes, body, self and situation are like the links of a chain, holding together and influencing each other and understood as a healthy transition. When balance is lost, one perspective becomes dominant and a struggle between different perspectives emerges. One could also choose consciously to prioritise a particular perspective, prioritising what felt most important at the moment, e.g. being able to eat as others or feeling good about a correct blood glucose level. This implies that bodily conditions, own wishes and circumstances in the life situation or life world (Dahlberg et al. 2008) cannot all be satisfied simultaneously. The learning process of living with diabetes is further understood as a fluctuation between objectifying a disease and integrating an illness. The objectified disease is separated from oneself and one’s life, whilst the illness is integrated as a subject into the person’s body, self and life world - the lived body (Merleau-Ponty 1945/2002).

In the present study, demanding situations could present an opportunity to learn to understand something in a new or different way, providing expanding knowledge, and a feeling of increased security. On the other hand, this becomes a struggle when one cannot make sense of the experienced situation, implying an experience of vulnerability or as Merleau-Ponty (1945/2002) writes; a disharmony. The present study shows a difference of behaviour as routines associated with different life events or as habits integrated within the person. Merleau-Ponty (1945/2002, p.164) writes that “*the acquisition of habit as a rearrangement and renewal of the corporeal schema*” empowers the person to respond to a situation. Habits are always both motor (body) and perceptual (mind), and habit gives the “*power of dilating our being-in-the-world or change our existence*” (Merleau-Ponty 1945/2002, p. 166). This gives us an understanding of the difference between incorporating a habit and using a routine, and also illuminates different ways of learning on a continuum from adapting to integrating.

In the present study there was a struggle between the perspectives of body, self and life situation when diabetes not was integrated into the lived body. Struggle is further described in studies as a loss, feeling of burden, diabetes distress or powerlessness (Mamhidir and Lundman 2004, Skovlund and Peyrot 2005, Peyrot et al. 2005, Aujoulat et al. 2007) or as a struggle between what one knows and what one wants, between what is socially accepted and such obstacles in life where change is a dilemma (Rush Micheal

1996, Lin et al. 2008,). This is also described by Mamhidir and Lundman (2004) who found a contradiction in that participants both wanted to live their lives as usual and to live them according to what they understood was the best for the disease. Auduly et al. (2009) describes an intra-personal conflict as tension between what participants with chronic illness felt to be preferable and what they experienced as possible. Of interest is the variation of the participants between different phases of integrating the illness into the lived body, despite having experienced the disease for the same length of time. Time as such, or length of experience, therefore does not seem to be vital for integrating diabetes into the lived body.

How a person experiences the physical body was found to be crucial in this learning process. If the body with its signals is understood as a subject, then it can be a tool for experiencing and understanding the world and oneself. Knowledge is then personalized and unique, meaning one's own interpretation is crucial for understanding one's own and others' experiences. Knowledge is also understood as something always carried along like an invisible rucksack, incorporated within the person, or embodied (Merleau-Ponty 1945/2002). This is further discussed by Mamhidir and Lundman (2004) and Rush Michael (2006): how the ability to deal with self-management and self-care was dependent on participants' understanding of their body. The meaning of freedom and control varies according to how diabetes is integrated. Control by others means that illness is objectified, a disease, whilst

control by oneself is more than merely controlling a disease - it is mastery of one's own life. At the same time, having an overall feeling of control is understood as finding balance, or harmony (Merleau-Ponty 1945/2002). This divergence in the concept of control is also found in other studies where control is understood as something negative or limiting (Lin et al. 2008), but also as something achievable, finding a balance between different parts in life (Johansson et al. 2009) or as understanding the body as well as daily life (Paterson et al. 1998). The present study also shows how differently a tool or instrument (e.g. the glucose meter) is experienced by the user. In the learning process the glucose meter was both a resource and an obstacle to understanding and to making sense of the changed conditions. More experience increased the possibility of understanding the meaning of the tools for oneself. Merleau-Ponty (1945/ 2002, p.176) argues that there is a difference between an external object and an instrument, since an instrument "providing an extension of the bodily synthesis", facilitates the way we experience the situation and ourselves. The present study finds the integrating process to be ongoing rather than linear. This is further discussed by Aujoulat et al. (2008) in terms of holding on and letting go, and as an on-going inner negotiation in decision-making (Auduly et al. 2009) for participants with various chronic illnesses. This is seen in the contradiction of wanting to be the "old me" and at the same time being changed and becoming the different "new me". The participants experienced diabetes as part of themselves but still wanted to be free from it. This can be

understood by Bridges' (1933/2009) descriptions of the neutral zone as in between the old and the new. By objectifying the disease the participant remains in the first phase, whilst by integrating diabetes in the lived body one is seen to be in the "new beginning". A pendulum can also be seen to swing between dependence and independence, when life events and changed body conditions can necessitate being more dependent than previously. Insecurity about one's own ability and knowledge means that others' knowledge and recommendations become crucial. This is in agreement with Aujoulat et al. (2008) and Auduly et al. (2009). Requirements for health care also vary, so it is crucial that the parties involved, including the health care system, are flexible in their encounters with the changing needs of those living with diabetes.

DISCUSSION OF STUDY LIMITATIONS

The selected sample approach enabled a variation in parameters such as age, working condition and gender. However, the heterogeneity regarding ethnicity, cultural and contextual condition is considered as a limitation of the study. The fact that all participants were recruited after a hospital visit may also have influenced their awareness and engagement in the transition process.

It is to be noted that, even if participants were recruited for the study in connection with a hospital visit when they had been diagnosed with diabetes, it was later found that some had previous experiences of being ill. This has probably influenced the transition process of living with diabetes. Meleis et al.(2000) also claim that transition in relation to chronic illness influences, and

is influenced by, other transition processes going on within the person. The experience within the transition to living with diabetes as a chronic illness with the inability to achieve normal glucose level was therefore of central importance for this study. Types of diabetes or their medical causes were not looked at in any detail . ADA (2003) also suggests that it is less important for people to label the type of diabetes than it is for them to understand the reason for hyperglycaemia and how to treat it effectively.

The interviews were conducted in Swedish and we need to be aware that all translation involves interpretation. Words may have a cultural meaning that is lost in translation, or an equivalent word may not always be found in another language. The authors have been aware of this and have chosen quotations carefully that can retain their substance when translated.

Learning was a word seldom actually used by the participants, but in their narratives the learning became apparent. This is in line with Kolb (1984), who discussed learning as often being spontaneous and unconscious for the person. With the findings and understanding from this study, one can ask if it had been more appropriate to ask about experiences concerning “situations that have affected you and which you had to handle in some way”. This would decrease the risk of separating and objectifying an integrated illness (Tang et al. 2006, Thors Adolfsson 2008) .

Whilst the researcher is the primary instrument in qualitative research, analysis and interpretation will vary with the orientations of each investigator

(Sandelowski and Barroso 2003), and according to Ricoeur (1976) there is always more than one way to interpret a text. Therefore, these findings presented the most useful understanding for the authors.

CONCLUSION

This study showed that duration of illness was not of importance for the understanding of living with diabetes. Living with diabetes three years after being diagnosed meant to experience both an overall balance in one's existence and a daily struggle. Managing interaction with others in order to share one's experiences, so important to a healthy transition when living with diabetes, was crucially dependent on the ability to interact in such situations. To be able to interact, participants had to understand their body as a unique subject, and the circumstances for their lives as unique. When diabetes was integrated into the lived body, living was in general experienced as simple, since decisions made always involved having diabetes. With the findings from this study, patient education in a group setting, with the goal of sharing experiences in a learning process, will be meaningful only if the person has the ability to interact with others.

REFERENCES

- ADA, American Diabetes Association (2003) Report of the expert committee on the diagnosis and classification of diabetes mellitus. *Diabetes Care* **26**, 5-20.
- Asbring P. (2001) Chronic illness - a disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing* **34**, 312-319.
- Auduly A., Norbergh K., Asplund K. & Hornsten A. (2009) An ongoing process of inner negotiation -- a Grounded Theory study of self-management among people living with chronic illness. *Journal of Nursing & Healthcare of Chronic Illnesses* **1**, 283-293.

- Aujoulat I., Luminet O. & Deccache A. (2007) The perspective of patients on their experience of powerlessness. *Qualitative Health Research* **17**, 772-785.
- Aujoulat I., Marcolongo R., Bonadiman L. & Deccache A. (2008) Reconsidering patient empowerment in chronic illness: a critique of models of self-efficacy and bodily control. *Social Science & Medicine* **66**, 1228-1239.
- Bridges W. (1933/2009) *Managing transitions : making the most of change*. Nicholas Brealey, London.pp. 3-164
- Charmaz K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness* **5**, 168-195.
- Dahlberg K., Dahlberg H. & Nystrom M (2008) *Reflective lifeworld research*. Studentlitteratur, Lund.pp.1-370
- Funnell M.M. & Anderson R.M. (2003) Patient empowerment: a look back, a look ahead. *The Diabetes Educator* **29**, 454-464.
- Genep A.V. (1960) *The rites of passage*. Univ. of Chicago Press, Chicago. pp.1-195
- Hernandez C.A. (1996) Integration: the experience of living with insulin dependent (type 1) diabetes mellitus. *The Canadian Journal Of Nursing Research* = *Revue Canadienne De Recherche En Sciences Infirmières* **28**, 37-56.
- Jarvis P., Holford, J., Griffin, C.(2003) *Human Learning - an holistic approach*. Routledge, Madison Ave, New York.pp. 1-240
- Johansson K., Ekebergh M. & Dahlberg K. (2009) A lifeworld phenomenological study of the experience of falling ill with diabetes. *International Journal of Nursing Studies* **46**, 197-203.
- King G., Cathers T., Brown E., Specht J.A., Willoughby C., Polgar J.M., MacKinnon E., Smith L.K. & Havens L. (2003) Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research* **13**, 184-206.
- Kneck Å., Klang B. & Fagerberg I. (2011) Learning to live with illness: experiences of persons with recent diagnoses of diabetes mellitus. *Scandinavian Journal of Caring Sciences*, **25**, 558-566
- Kolb D.A. (1984) *Experiential learning : experience as the source of learning and development*. Prentice-Hall, Englewood Cliffs, N.J.pp. 1-231

- Kralik D. (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* **39**, 146-154.
- Kralik D., Koch T., Price K. & Howard N. (2004) Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing*, **13**, 259-267.
- Lin C., Anderson R.M., Hagerty B.M. & Lee B. (2008) Diabetes self-management experience: a focus group study of Taiwanese patients with type 2 diabetes. *Journal of Nursing & Healthcare of Chronic Illnesses* **17**, 34-42.
- Lindseth A. & Norberg A. (2004) A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences* **18**, 145-153.
- Mamhidir A. & Lundman B. (2004) Having control over type 2 diabetes means daring to be free. *Journal of Diabetes Nursing* **8**, 12-16.
- Meleis A.I., Sawyer L.M., Im E.O., Hilfinger Messias ,D.K. & Schumacher K. (2000) Experiencing transitions: an emerging middle-range theory. *ANS,Advances In Nursing Science* **23**, 12-28.
- Meleis A.I. (2010) *Transitions Theory; Middle-Range and Situation-Specific Theories in Nursing Research and Practice*, Springer Publishing Company, New York.pp. 1-641
- Merleau-Ponty M. (1945/2002) *Phenomenology of perception*. Routledge, London.pp.3-539
- Merton R.K. (1973) *The sociology of science : theoretical and empirical investigations*. Univ. of Chicago Pr., Chicago. pp.1-636
- Norris S.L., Lau J., Smith S.J., Schmid C.H. & Engelgau M.M. (2002) Self-management education for adults with type 2 diabetes: a meta-analysis of the effect on glycemic control. *Diabetes Care* **25**, 1159-1171.
- Paterson B.L. (2001) The shifting perspectives model of chronic illness. *Journal Of Nursing Scholarship: An Official Publication Of Sigma Theta Tau International Honor Society Of Nursing / Sigma Theta Tau* **33**, 21-26.
- Paterson B.L., Russell C. & Thorne S. (2001) Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing* **35**, 335-341.
- Paterson B.L. (2003) The koala has claws: applications of the shifting perspectives model in research of chronic illness. *Qualitative Health Research* **13**, 987-994.

- Peyrot M., Rubin R.R., Lauritzen T., Snoek F.J., Matthews D.R., Skovlund S.E. (2005) Psychosocial problems and barriers to improved diabetes management: results of the cross-national Diabetes Attitudes, wishes, and Needs study. *Diabetes Medicine* **22**, 1379-1385
- Piaget J. (1929) *The child's conception of the world*. Rowman & Littlefield, Totowa.pp.1-397
- Polit D.F. & Beck C.T. (2009) *Essentials of nursing research : appraising evidence for nursing practice*. Wolters Kluwer Health/Lippincott Williams & Wilkins, Philadelphia PA.pp. 1-610
- Price M.J. (1993) An experiential model of learning diabetes self-management. *Qualitative Health Research* **3**, 29-54.
- Ricoeur P. (1976) *Interpretation theory : discourse and the surplus of meaning*. Texas Christian Univ. Press, Fort Worth, Tex.pp. 1-95
- Rush Michael S. (1996) Integrating chronic illness into one's life. *Journal of Holistic Nursing*, **14**, 251-267.
- Sandelowski M. (1993) Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS.Advances In Nursing Science* **16**, 1-8.
- Sandelowski M. & Barroso J. (2003) Writing the proposal for a qualitative research methodology project. *Qualitative Health Research* **13**, 781-820.
- Schultz A. & Luckmann T. (1973) *The structure of the Life-World* Northwester University Press, Evansto US.pp. 1-335
- Skovlund S.E.,Peyrot M. (2005) on behalf of the DAWN International Advisory Panel: The diabetes Attitudes, Wishes, and Needs (DAWN) program: a new approach to improving outcomes of diabetes care. *Diabetes Spectrum* **18**, 136-142
- Snoek F.J., Kersch N.Y.A., Eldrup E., Harman-Boehm I., Hermanns N., Kokoszka A., Matthews D.R., McGuire B.E., Pibernik-Okanovic M., Singer J., de Wit M. & Skovlund S. (2011) Monitoring of Individual Needs in Diabetes (MIND): baseline data from the Cross-National Diabetes Attitudes, Wishes, and Needs (DAWN) MIND study. *Diabetes Care* **34**, 601-603.
- Tang T., Funnell M.M. & Anderson M. (2006) Group education strategies for diabetes self-management *Diabetes Spectrum*, **19**, 99-105.

- Tang T.S., Funnell M.M., Brown M.B. & Kurlander J.E. (2010) Self-management support in "real-world" settings: an empowerment-based intervention. *Patient Education and Counselling* **79**, 178-184.
- Thorne S., Paterson B. & Russell C. 2003, "The structure of everyday self-care decision making in chronic illness", *Qualitative Health Research*, **13**, 1337-1352.
- Thors Adolfsson E. (2008) Patient Education for People with Type 2 Diabetes in Primary Health Care. In *Medical Sciences* Vol. doctoral Uppsala University, Uppsala.pp. 11-61
- Thunander M., Petersson C., Jonzon K., Fornander J., Ossiansson B., Torn C., Edvardsson S. & Landin-Olsson M. (2008) Incidence of type 1 and type 2 diabetes in adults and children in Kronoberg, Sweden. *Diabetes research and Clinical Practice* **82**, 247-255.
- Vég A. (2006) Teaching and Learning in Type 2 Diabetes- The Importance of Self-Perceived Roles in Disease Management. In *Dep. of Public Health and Caring Sciences, Health Services Research, Uppsala Science Park*, Vol. Doctoral Thesis Acta Uppsala University, Uppsala.pp. 9-60
- Whittemore R. & Dixon J. (2008) Chronic illness: the process of integration. *Journal of Clinical Nursing* **17**, 177-187.